

From the desk of Henry: The Mark of Polio

By Henry Holland

SCRIBBLE

***To be crippled
To sit in a twist
Unable to be straight.***

***To reach out and topple over into the bend.
No balance at all.***

***Scoliosis
The mark of polio
Uneven as a scribble
No way to unwind and rest.***

An American female polio survivor wrote the poem above. The author prefers to remain anonymous. She had polio at age two and she suffered significant paralytic damage from the neck down. Like so many severely damaged polios, she spent much of her childhood trying to walk with two braces and crutches. She was unable to attend school away from home until her high school years. She eventually earned an undergraduate and masters degrees and worked until Post-Polio Syndrome (PPS) ended her career. She had no choice but to commit to a wheelchair as a teenager and a power chair as an adult woman. For years she drove her own van equipped with hand controls. Like many confined to wheelchairs, she drank almost no fluids during the day in order to avoid using non-handicapped restrooms while at work. PPS has taken its toll on her. She is essentially quadriplegic. She has a lifting apparatus to lift her from her bed to her wheelchair and back as well as to lift her from her wheelchair to the toilet seat and back. As a result of polio, she has scoliosis. Recently when she was sitting in her bed, she fell over because of her weakened back muscles and could not get upright again. During this time of helplessness, she thought of the words for her poem. She was successful in getting one of the lift straps under her chin and with some struggle, was able to return to a sitting position. In regard to the poem, she explained,

“The poem poured out of me because the minutes before I was unable to sit up - I kept falling over to the right. I felt like a corkscrew. The left side of my back has no muscles, so those on the right, when used, pull me over.”

Much has been written about the pain, new weakness, and fatigue of PPS. Much has been written about the changes in lifestyle that PPS demands and much has been written about the various modalities of treatment and recommendations to help PPSers. I have written my share of articles on these topics. Many polio survivors, who were fortunate to achieve good recoveries, now have to deal with

PPS. Many writers refer to these PPSers as “passers” because for so many years they “passed as normal.” From my perspective the “passers” conquered polio, but were caught off guard by PPS and were often misjudged by medical professionals because they had no visible marks of polio.

I would like to write a few words about the many polio survivors who were left with some mark of polio. They were left with a deformity as a result of acute polio. “Scribble’s” author is one of them. I am one of them. I use the word deformity because that word captures the shame, the horror and the emotional pain of a perception that is real. There are countless deformed polio survivors around the world. Many are too disabled to attend support group meetings. Many do not have computers. I know that these people are out there and hopefully are on the mailing list of some Post-Polio support group’s mailing list. If you are on this group’s mailing list, then hopefully you are reading this newsletter. This group of survivors has overcome incredible obstacles at a time when most cripples were kept out of the public eye. And even when one managed to achieve an entrance to the public eye, one can never forget the stares, the reactive expressions of fear, and the desire to avoid such encounters. Most of us learned the almost automatic reflex to present an outer expression of contentment and joy. Many of us developed wit and humor to distract others. One had to smile because tears were not a possibility. Tears invited pity and being crippled was bad enough. The author of “Scribble” wrote the following to me:

“Yes, you must write about deformity. It makes no sense to me, but a withered arm or leg is enough to crush some people. A deformed face is the worst of deformities. And number two is the back. Both are impossible to hide. I am not consoled to understand it is inborn, a survival mechanism that keeps others away from the sick and possibly harmful. I couldn't have married the elephant man, and for that I sit judged and condemned. Maybe I could have married the elephant man, but it would have taken years to see the beauty in his eyes. But he wouldn't have had beauty in his eyes because he would have been defensive and frightened. He would anticipate the gasps - involuntary gasps - from those who saw him without extensive preparation and maybe a good shot of whiskey. I understood this, and when I got out in the world, I realized I had to be personable, funny, smart, kind, and funny again. I had to be on, all the time. It was my part of the social contract. It was exhausting, especially in the early years when I was scared to death of people's reactions to me. These reactions were uniformly negative. I got it together in the 70s, but that was my hippie time, but it also was the times, as the times - they were a-changing.”

We have all benefited from “the times a-changing.” But most of us with the mark of polio had adapted to an unchanged world long before the social revolution of the late sixties and seventies. The ADA law of 1990 found most of us in middle age. We can now go to many restaurants, hotels, concerts, plays, parks, malls, and even airplanes because of the ADA and greater accessibility. Modern technology has made life easier for us. Mobile power chairs, scooters, vans with lifts, and hand-controlled vehicles give us greater mobility and freedom. Ventilators have both prolonged lives and retained some quality of life. A ventilator has prolonged my life for thirty-five years. Many PPSers are now using C-pap, Bi-pap and volume ventilators and these machines are prolonging livable lives. Many of us have bolstered the business of power wheelchair and scooter

manufacturers. We often can use the help of advocates in finding ways to financially afford necessary modern technology.

And the Lord put a mark on Cain, so that no one who came upon him would kill him. Then Cain went away from the presence of the Lord, and settled in the land of Nod, east of Eden. (Genesis 4:15b – 16)

As children or young adults many of us found our own inner lands of Nod. Nod was an inner lonely world where total understanding was absent and an explanation for the “why me’s” was silence. Many of us may have sought and found spiritual comfort where others perhaps felt unnoticed or forgotten by God. I do not believe that God is responsible for the mark of polio nor do I believe that God has abandoned the deformed. The ministry of Jesus of Nazareth included much healing, including the healing of the deformed. Two verses in Matthew address and summarize his healing ministry:

Great crowds came to him, bringing with them the lame, the maimed, the blind, the mute, and many others. They put them at his feet, and he cured them, so that the crowd was amazed when they saw the mute speaking, the maimed whole, the lame walking, and the blind seeing. And they praised the God of Israel. (Matthew 15: 30 – 31)

For so many with the deformities of polio, polio is a life long process. We are older, weaker, tired, hurting and less defended. We benefit from the understanding of our loved ones and each other. I encourage you to share your story with your family, the younger generation, and with us.

Before I conclude these thoughts, I often think about, remember, and hope I never forget those many polio victims who have already died from polio. There were many who died from the acute disease. They never had a life beyond polio. There were others who died from complications of polio in the early decades after polio. Their lives were shortened and often incomplete. If you have a mark of polio, try to move away from your inner land of Nod and return to Eden, but be sure to tell the people in Eden about your experience in Nod. Otherwise they will never know.

References:

1. Poem “Scribble,” author anonymous and excerpts from E-mail. May 2002
2. Meeks, Wayne A., Editor, *Harper Collins Study Bible, New Revised Standard Version*, Harper Collins Publishers, New York, 1993.